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Twenty Years of AIDS in America --- Spotting AIDS in Africa Shaped Doctor's Destiny

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This week, Anne Bayley is going back to Zambia, the country where she first worked as a missionary doctor in 1961. Since then, Zambia has been transformed utterly by the disease -- AIDS -- that Dr. Bayley first identified there. But she, too, has been changed by her discovery.

The story of this unassuming, British-born woman -- who will turn 67 years old tomorrow -- is a classic medical detective tale; but more than that, it is an account of the profound and lasting impact AIDS had on the epidemic's early front-line doctors.

The very first scientific report anywhere in the world about the disease appeared on June 5, 1981, in the Mortality and Morbidity Weekly Report of the Centers for Disease Control. That article describes five homosexual men in Los Angeles, three of them found by physician Michael Gottlieb, who to this day remembers their names and life stories. Those patients were the first of "hundreds of people in my care that died horrible deaths," Dr. Gottlieb says.

AIDS almost certainly arose in sub-Saharan Africa. But it apparently spread slowly at first, and through some of the poorest stretches of the continent, where access to research institutions was at best rare. By the early 1980s, a few doctors and village healers had noticed an incurable illness that slowly wasted patients into skin-shrouded skeletons -- "Slim," they called the illness on the border of Uganda and Tanzania. But overwhelmed with the usual diseases of poverty, these medics had little opportunity for formal investigations.

Even when the reports of AIDS in the U.S. and Europe started coming out, most physicians in Africa

figured that an illness of white American homosexuals was one thing they didn't need to worry about. But a handful of doctors working in different parts of the continent did begin to make the connection. Dr. Bayley was the first to do so in Zambia, and one of the first anywhere in Africa.

In the early 1980s, Dr. Bayley was an associate professor of medicine at the university teaching hospital in the Zambian capital Lusaka. She also ran a tumor clinic that specialized in a cancer called Kaposi's sarcoma, or KS, which was not uncommon among older East African men.

But the KS she and other African doctors were accustomed to seeing was fairly mild. The signature purple skin patches of the disease appeared on the ends of the limbs, "almost never above the knee or elbow," she says. So, she recalls, "I was somewhat surprised that in 1981 and '82, I got papers regularly about a strange new disease" among young American and European homosexuals that featured an aggressive form of KS, in which purple lesions erupted all over the body and even ravaged the internal organs.

In January 1983, a patient was referred to Dr. Bayley with nothing more than persistent swollen lymph nodes. She thought the patient probably had lymphoma, a cancer of the lymph nodes. The last thing she suspected was KS, but that is what a biopsy revealed. "I went back and examined him in minute detail and found nothing on his skin," she recalls. "But I did find one tiny purple patch in his mouth."

That same month, another patient came in, just 22 years old, with KS patches on his trunk, neck and face. That was remarkable enough, but an endoscopy revealed "multiple purple lumps in his stomach, gullet, esophagus, and duodenum," or small gut, she recalls.

"I knew almost at once what was happening," Dr. Bayley says. By the end of 1983, she had seen 13 patients with the aggressive form of KS, eight of whom had died. Her intuition that they had AIDS was bolstered by blood tests, showing that they had the same deficits in immune-system T-cells seen in the American patients.

Other doctors were less certain. In Uganda, David Serwadda, now a renowned AIDS researcher, had seen four patients with the new, aggressive KS, and he had read medical articles about the American homosexuals with similar symptoms. But unlike Dr. Bayley, he wasn't convinced his patients had AIDS. He recalls, "I was thinking, 'The disease is here already? Even in black heterosexual women?' "

The association of AIDS with homosexuality was probably the single biggest obstacle that inhibited scientists -- in Africa and America -- from accepting that AIDS could be spread through heterosexual intercourse.

As for Dr. Bayley, she interviewed her patients and was convinced that homosexual activity wasn't a factor. But that made her frightened that she might "pick it up from just handling my patients," she

recalls. Only after a year had passed and she hadn't developed any of the symptoms of the disease did her fear begin to recede.

In 1984, the opportunity arose to finally determine whether the disease killing Africans was the same one slaying American gay men. That was the year the AIDS virus -- HIV, then called HTLV-III -- was discovered and an antibody test developed. Dr. Bayley sent her samples to British virologist Robin Weiss, along with the sealed codes of patients she thought would test positive. "I wasn't 100% accurate," she recalls, "but I was pretty much right."

Dr. Serwadda's four patients also tested positive. "That's when it dawned on us," he says. AIDS was in Africa.

But how many cases? Dr. Bayley had been plotting a graph of all the patients she suspected of having the disease. While the total number of cases in Zambia was still small, she recalls, "by the end of 1984 I had enough points on my graph to know it was an exponential curve" -- an exploding epidemic. But the Zambian ministry of health, she recalls, used the small total number to dismiss the skyrocketing trend.

At about this time, reports of Slim had made it into Ugandan newspapers, and a brash surgeon named Wilson Carswell organized an investigational expedition to southern Uganda. The group included Drs. Bayley and Serwadda and three others. But it was Dr. Bayley who played the critical role in this landmark investigation.

On Sunday, June 2, 1985, the team visited a hospital in Masaka, Uganda. There, Dr. Bayley recalls, she "walked around the ward with a doctor's curiosity." Incorporating AIDS manifestations being reported from America and Europe with her own observations in Zambia, she had developed a clinical diagnosis of AIDS — a constellation of symptoms that included persistent swollen lymph nodes, a fungal infection of the mouth called thrush and "a red wet soggy throat, like a schoolchild with a viral infection, and very enlarged tonsils." With all that in mind, she quickly realized the hospital was awash with AIDS.

On that Sunday, Dr. Bayley screened 109 people. Using her self-taught diagnosis, she identified 29 as having the symptoms of HIV. Every one of those 29 ended up testing positive for the virus. "I was shattered," Dr. Bayley recalls. "That was the definitive moment when I recognized the magnitude of the epidemic."

African authorities, defensive at the implication their countries were saturated with a sexually transmitted disease, were much slower to react. Even Uganda, now a leader in the response to AIDS, took a couple of years to fully mobilize. To this day in Africa, the stigma of AIDS hinders efforts to stop

the disease, as do tattered public-health systems and poverty. Consequently, the virus has spread relentlessly through sub-Saharan Africa.

As for Dr. Bayley, the epidemic swept her along "like the waters below Victoria Falls," as she puts it. She helped organize everything from surveys of the disease to prevention and care programs. By the late 1980s, she recalls, "I was dealing often -- well, all the time – with people who were facing the ultimate questions of death and dying." In this crucible, she says, her childhood desire to join the priesthood "resurfaced and wouldn't go away."

In 1990, Dr. Bayley left Zambia for theological training in England. Behind her decision, she says, was a "sense of the inadequacy of physical medicine to deal with HIV/AIDS."

Dr. Bayley was ordained an Anglican priest in 1994. Despite the overwhelming devastation of the plague, "what I missed more than anything else was contact with my HIV-infected patients," she says. She says she "never saw AIDS as a punishment, as some Christians did, and I didn't see it as a defect in the underlying plan, so to speak."

She remembers one man who tested HIV-positive who had slept with quite a lot of women. "We sat down and talked about it, and I said, 'You are infectious and you have a responsibility for your sexual partners.' And he looked at me and said, 'I've stopped.' There was no hint in his demeanor that he was saying something to please me. Indeed, he looked as astonished as I was." The next time he came to the hospital, "he brought me a gift -- a necklace made of one of the local stones -- which I treasure. It was an acknowledgment that we shared an important moment: he having changed his sexual behavior radically, and me recognizing how difficult that was and respecting and appreciating him for having done so."

On her coming trip to Africa -- one of many she has made since she was ordained -- Dr. Bayley will also visit Malawi, where an Anglican bishop has asked her to run some HIV workshops. She is officially retired from medicine and the priesthood, but AIDS, she says, "continues to shape my life." She adds: "Every time I think I'm closing the books on HIV, I get asked to do something else."

(See related article: "Blacks Now Account for Half Of All New HIV Infections; Homosexuality Still Taboo" -- WSJ May 30, 2001)

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